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Facebook for Support versus Facebook for Research: The Case of Miscarriage

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ABSTRACT

Researchers use Asynchronous Remote Communities (ARC) to reach out to target populations who may find it hard to meet in person, or make time for telephone interviews. So far, ARC studies have been conducted using closed and secure groups on Facebook, because most participants are active members of this social network. However, it is not clear how participants' Facebook usage might affect their engagement with an ARC study. In this paper, we report a secondary analysis of a recent ARC study of women who had experienced at least one miscarriage that focused on their information and social support needs. We find participants tend to be comfortable with seeking emotional support on Facebook, and even those who say they rarely post to Facebook engage with most group activities. We discuss implications for choosing platforms for ARC studies.

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KEYWORDS

social media; miscarriage; women's health;
Facebook; online research methods

Table 1: Demographics. SG= Star Gazers. SC= Star Catchers. 1 participant in Star Gazers did not provide demographic data

	SG (n=21) N (%)	SC (n=21) N (%)	Total
Currently Based			
United Kingdom	10 (48)	8 (38)	18
United States	10 (52)	13 (61)	23
Age Group			
25-29	2 (10)	3 (14)	5
30-34	6 (30)	5 (24)	11
35-39	7 (35)	9 (42)	16
40-44	2 (10)	3 (14)	5
45-49	2 (10)	-	2
50 and above	1 (5)	1 (5)	2
Self-reported Facebook log in frequency			
Daily	18 (90)	19 (90)	37
4-6 times per week	2 (10)	2 (10)	4
Self reported Facebook posting frequency			
Daily	1 (5)	3 (14)	4
4-6 times per week	2 (10)	2 (10)	4
2-4 times per week	2 (14)	3 (14)	5
Once a week	5 (24)	2 (10)	7
Rarely	10 (47)	11 (52)	21

INTRODUCTION

Asynchronous Remote Communities (ARC) is a useful group-based method for engaging with people who find it hard to attend face to face interviews or focus groups. In a typical ARC study, participants take part in a series of moderated activities over 8–12 weeks in a closed, secret Facebook group. Activities can be private, such as completing a survey off Facebook, or public, such as discussing a post. MacLeod et al. [4] piloted the ARC method with people with rare diseases to gain a deeper understanding of their challenges and needs. The method has also been used successfully for pregnant women and new mothers [6] and people living with HIV [5]. Kresnye et al. [3] summarises the lessons learned in conducting these studies. All ARC studies so far were predicated on the assumption that Facebook, despite its many security flaws, was an appropriate medium because most participants already use the platform to reach out to others. In this paper, we unpack this assumption based on a recent ARC study of women who have experienced miscarriage and contextualise our findings with recent work on online social support for women who have miscarried [1].

Women may avoid openly speaking about their miscarriage in face-to-face conversation [2]. It can be even more difficult to talk about miscarriage to a wide network of acquaintances. However, for some women, Facebook can make it easier to self-disclose and can provide safe and comfortable spaces to talk about their concerns and thoughts [1].

The focus of this ARC study was to determine the information and social support needs of women before, during, and after miscarriage. We recruited participants from the United States (US) and the United Kingdom (UK), two countries that share a common language, but have vastly different health care systems and approaches to perinatal care. Perinatal care in the US is led by obstetricians, while care in the UK is led by midwives and family doctors, with obstetricians only involved in case of complications. We examine to what extent participants' self-reported use of Facebook is reflected in their engagement in the ARC activities. In this context, we also investigate how participants use Facebook to access social support, and how Facebook compares to other platforms they use.

METHOD

Forty-four women were recruited and assigned to two groups. The Star Gazer (SG) group involved those who did not have a live birth after their last miscarriage, while participants in the Star Catchers (SC) group had at least one live birth afterwards. Two individuals in SC dropped out after the first few weeks due to personal reasons. One woman from SG did not complete the demographics survey, but completed three activities. As Table 1 shows, SG and SC are balanced in terms of age, but SC has more participants from the US. IRB approval was granted by Indiana University.

Table 2: Activities Used in Study. W= Week. T= Type of the Activity (FT= Free Text, M= Media, S= Survey). N= No. participants who completed the activity. Total N=42

W	Activity	T	N (%)
1	A1: Meet and Greet	FT	37 (88)
	A2: Facebook Availability	Poll	38 (90)
2	A3: Drawn Timeline	M	36 (86)
	A4: Emotional Wellbeing Scale	S	40 (95)
3	A5: Dear Abby	FT	28 (66)
	A6: Miscarriage Experience	FT	32 (76)
4	A7: Circle Diagram	M	22 (52)
	A8: Brief Cope	S	35 (83)
5	A9: Social Support Network	FT	25 (59)
	A10: Social Support	S	35 (83)
6	A11: Coping Mechanisms	FT	25 (59)
	A12: Missing Information	FT	21 (50)
7	A13: Importance of Info	S	30 (71)
	A14: Technology Use	S	32 (76)
8	A15: Future Technology	S	34 (81)
	A16: Goodbye	FT	4 (10)

Activities

The ARC study consisted of 16 activities posted at regular times over 8 weeks (c.f. Table 2). The main research activities (A3-A15) involved writing about participants' own experiences (Free text, $n = 5$), surveys (survey, $n = 6$), and posting a drawing (media, $n = 2$; some participants responded using free text). Free text and media activities were shared in the group, while surveys were private. Each research activity was triangulated with at least one other. Here, we focus on data from three activities that looked at social media usage in general and for social support in particular. These are social support network (A9), the social support survey (A10), where we asked women about their social networks and sources of support before and after miscarriage, and Technology Use (A14), where women shared the social media platforms and internet resources they used to seek and access support and information. Additional relevant information came from activities A3, A5, A6, A8, and A11.

Data Analysis

Quantitative data are reported using descriptive statistics. Qualitative data were coded by two researchers (MA and CK) independently using content analysis, with top-down codes derived from the research questions. MA and CK agreed on a codebook from the codes, and data were re-coded.

FINDINGS

Frequency of Facebook Usage and ARC Engagement

As Table 3 shows, Facebook is the only common platform that participants regularly use. However, around half of the participants only post rarely (c.f. Table 1). Activity completion ranges between 47-76% for the five free text activities, and between 71-83% for the six surveys; as usual, completion rates decreased over the course of the study.

While there is no clear relationship between posting frequency and completion of free text activities, those who state that they only post rarely also only complete on average 3 out of 5 free text activities (c.f. Fig. 1). Interestingly, daily posters show a similar pattern.

Facebook as a Source of Support and Information

In the technology usage survey (A14, 32 respondents), we asked women about the social media platforms used for practical support, emotional support, recovery, information about health care, information about miscarriage, and other issues related to miscarriage. The most popular sources were Facebook, blogs, and forums—all other platforms (YouTube, Twitter, SnapChat, and Instagram) were named less than five times for each of the categories.

For all categories except for practical and emotional support, we saw a similar pattern: Over two thirds of participants (range: 20 (62.5%)—24 (75%)) use online forums (blogs: 10 (31%)—15 (47%);

Table 3: Frequency of Use of Social Platforms. Messenger = Facebook Messenger; IM: Instant Messenger.

	Daily N (%)	Weekly N (%)	Rarely N (%)	Don't have N (%)
Facebook	40 (98)	1 (2)	-	-
Messenger	17 (42)	16 (39)	6 (14)	2 (5)
WhatsApp	13 (32)	8 (19)	6 (15)	14 (34)
Skype	6 (14)	13 (32)	17 (42)	5 (12)
SnapChat	5 (12)	4 (10)	9 (22)	23 (56)
Twitter	3 (7)	6 (15)	16 (39)	16 (39)
IM	3 (7)	2 (5)	8 (20)	28 (68)
LinkedIn	-	5 (12)	21 (51)	15 (37)
Line	-	-	4 (10)	37 (90)
WeChat	-	-	1 (2)	40 (98)

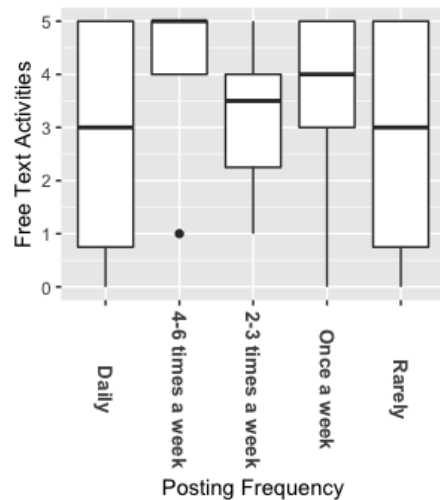


Figure 1: Completion of Free Text Activities and Facebook Posting Behaviour

Facebook: 7 (22%)—11 (34%)). When it comes to practical support, however, forums (19 women; 59%) and Facebook (18 women; 56%) are used equally often, with blogs at 22%. Facebook is a key source of online emotional support for 20 women (62.5%), followed by forums (15, 47%) and blogs (5, 16%).

In A10 (35 respondents), we asked participants about the social groups and activities used before and after miscarriage, such as Facebook groups; online forums; church / religious groups; social groups such as book clubs; sport, such as Tennis; exercise or fitness classes such as Yoga; non-profits / charities; and parent groups. Facebook groups were the most popular groups both before ($n = 25$, 72%) and after ($n = 28$, 80%) miscarriage. While two women (1 SG, 1 SC) stopped relying on Facebook groups after miscarriage, five Star Catchers joined them. Membership of online forums ($n = 11$, 34%) remained constant, as did membership of other types groups. The main exception were fitness classes. 21 (60%) attended before their miscarriage, but only 16 (45%) afterwards

For 32 women, we have demographic information as well as responses to A10 and A14. 15 of those women (47%) posted on Facebook less than once a week, 11 (25%) posted 1–3 times per week, and 6 (19%) posted at least four times per week. As expected, regular posters are more likely to use Facebook for practical and emotional support, and more likely to be part of Facebook groups (c.f. Table 4).

How Women Leverage Facebook for Social Support

Consistent with previous findings [1], participants appropriated Facebook in many different ways. Some used the platform to document a miscarriage or to notify their network about it; reaching out to close friends sometimes brought comfort. Others used Facebook to educate others and raise awareness of the pain of miscarriage, and some did not mention their miscarriage on Facebook at all.

I have also shared our loss on Facebook so a lot of people will know. I think without Facebook, I would have wanted to mention the miscarriage more so it wouldn't feel like a secret.[SG20, A9]

I posted information about how basically losing a pregnancy is hard and just as hard as losing a friend or family member and to think about the phrasing used. [SG06, A9]

When women proactively sought help through Facebook groups, these did not have to be pregnancy and parenting related, and could fulfill functions similar to online forums.

I also would ask on online forums/Facebook groups if any friends could point me at useful resources.[SC12, A14]

If there were something I'd post anonymously to a Facebook group of [PROFESSIONAL WOMEN] to ask for input and different perspectives (you can email admins and they'd post anonymously).[SC21, A10; name of group redacted]

Other participants saw Facebook as a necessary part of their grieving process, and it helped them cope with negative emotions after miscarriage.

I wanted my friends to know about the miscarriage because for me it helps to talk about it, and it's a big part of my life. In December I posted about my miscarriage on Facebook and got lots of support.[SG20, A6]

Importantly, the connections can be crucial in overcoming feelings of loneliness and awkwardness. For example, [GROUP NAME] is a closed facebook group that enables free flow of conversation between women who have experienced miscarriage, stillbirth, or the death of a child. [SG10, A5; name of group redacted]

DISCUSSION

The findings show that the main advantage of using Facebook as an ARC platform is its wide reach. As we have seen, even though many participants were mostly “lurkers” on Facebook, they visited the site regularly, and it was the most common platform used by participants. This shared platform allowed for interactions between participants thousands of miles apart, all while avoiding the difficulty of face-to-face conversations. In this ARC study, we achieved high participant engagement and retention, with 81% completing our last data collection activity, A15. We believe that this is at least partly due to our choice of Facebook as a platform where participants were already active.

While notifications on the platform can be adjusted, adding participants to a research group can blur the line of usage. Notifications of study activities will be mixed in with typical messages (e.g. tagged in a photo, response to a comment). This worked well for our study as we posted two activities a week, but can potentially be bothersome to participants if the notifications flood out their normal messages. This is particularly vital to protect against in populations that are currently using Facebook for support, because they may have adjusted their notification settings to focus on messages from close friends.

Unlike MacLeod et al [4], we found that participants were less likely to complete free text activities that allowed them to remain on the platform. Instead, surveys had better overall completion rates (c.f. Table 2). Many of the free text activities required participants to tap into potentially emotional memories, which might have caused them to struggle with an activity or skip it entirely. Another reason is the diversity of experiences and cultural backgrounds, which might have led participants to self-censor. For example, not all Star Gazers had children; some women had recurrent miscarriages, while others did not; and some women had experience of fertility treatment. These differences highlight the importance of study design being tailored uniquely for a given population when using ARC.

IMPLICATIONS FOR ARC

At the time of writing (early 2019), the main advantages of hosting ARC studies on Facebook appear to be its wide reach in the Western world, which is currently hard to replicate on another platform, and the mechanism of closed, secret groups, which affords at least some privacy and confidentiality.

Table 4: Self-Reported Facebook Posting Frequency and Facebook Use for Miscarriage Support.

	>3 × wk	1-3 × wk	< 1 × wk
Use of Facebook Groups			
Before Miscarriage	5 (83%)	9 (82%)	9 (60%)
After Miscarriage	6 (100%)	10 (90%)	11 (73%)
Support Through Facebook			
Emotional	6 (100%)	7 (64%)	7 (47%)
Practical	5 (83%)	6 (55%)	7 (47%)

ARC researchers should monitor the social media landscape to detect emerging alternatives, such as WhatsApp and Skype, and review their privacy policies and practices.

While most participants were comfortable with disclosing and discussing painful experiences on Facebook, and actively used the platform to seek out emotional and practical support, others were not, and this may have been exacerbated by participants' diverse reproductive histories. Future ARC studies might want to consider smaller, more fine grained groups.

As highlighted in our discussion, future ARC studies should be mindful of potential effects of study involvement for participants, particularly with notifications. Along with this, extra care should be placed into activity design to avoid unintentional emotional burdens for participants, like piloting activities in the targeted populations..

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REFERENCES

- [1] Nazanin Andalibi and Andrea Forte. 2018. Announcing Pregnancy Loss on Facebook: A Decision-Making Framework for Stigmatized Disclosures on Identified Social Network Sites. *Proceedings of the ACM SIGCHI Conference on Human Factors in Computing Systems (CHI 2018)* March (2018). <https://doi.org/10.1145/3173574.3173732>
- [2] Clare Bellhouse, Meredith J Temple-smith, and Jade E Bilardi. 2018. "It ' s just one of those things people don ' t seem to talk about ... " women ' s experiences of social support following miscarriage : a qualitative study. (2018), 1–9.
- [3] K. Cassie Kresnye, Juan F. Maestre, Ben Jelen, Mona Y. Alqassim, Maria K. Wolters, and Katie A. Siek. 2019. Lessons Learned from Conducting Group-Based Research on Facebook. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems - CHI '19*. <https://doi.org/10.1145/3290607.3299055>
- [4] Haley MacLeod, Ben Jelen, Annu Prabhakar, Lora Oehlberg, Katie Siek, and Kay Connelly. 2017. A Guide to Using Asynchronous Remote Communities (ARC) for Researching Distributed Populations. *EAI Endorsed Transactions on Pervasive Health and Technology* 3 (07 2017), 152898. <https://doi.org/10.4108/eai.18-7-2017.152898>
- [5] Juan F Maestre, Haley Macleod, Ciabhan L Connelly, Julia C Dunbar, Jordan Beck, Katie A Siek, and Patrick C Shih. 2018. Defining Through Expansion : Conducting Asynchronous Remote Communities (ARC) Research with Stigmatized Groups. (2018). <https://doi.org/10.1145/3173574.3174131>
- [6] Annu Sible Prabhakar, Lucia Guerra-Reyes, Vanessa M. Kleinschmidt, Ben Jelen, Haley MacLeod, Kay Connelly, and Katie A. Siek. 2017. Investigating the Suitability of the Asynchronous, Remote, Community-based Method for Pregnant and New Mothers. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems - CHI '17* (2017), 4924–4934. <https://doi.org/10.1145/3025453.3025546>